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ABSTRACT

This report examines possible steps the State of Illinois might take to expand the availability of Medicaid support for services to persons with developmental disabilties. Stressed throughout are the importance of: (1) evaluating whether any given application of Medicaid funding is consistent with the State's goals for persons with developmental disabilties; and (2) establishing the necessary administrative infrastructure at the state and sub-state level to support efficient and effective service delivery. Current utilization of Medicaid to fund developmental disabilities services is outlined and a table compares the percentage of costs of institutional and community-based services for Illinois and other Midwestern states. Noted is that Illinois is well below the national median in amount of federal assistance obtained. The policymaking context in Illinois is then considered. Implications of current Medicaid financing policies are examined for the following: Intermediate Care Facilities for the mentally retarded (financing and compliance with federal standards need to be linked); nursing home reform; the home and community-based waiver authority; optional case management services; early periodic screening, diagnosis and treatment; and other Medicaid services (personal care services, Medicaid rehabilitation and clinic services, and educationally related services). (DB)

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# UTILIZING MEDICAID DOLLARS TO FINANCE SERVICES TO ILLINOIS CITIZENS WITH DEVELOPMENTAL DISABILITIES

A Technical Assistance Report
Prepared for the
Illinois Planning Council on
Developmental Disabilities
and the
Illinois Department of Mental Health and
Developmental Disabilities

by

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National Association of State Mental
Retardation Program Directors

January 7, 1991

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## I. INTRODUCTION

During its 1989 session, the Illinois Legislature established an advisory committee to prepare a developmental disabilities services implementation plan for the State (P.L. 86-921). The intent of this plan, as envisioned in the legislation, was to sketch out the principal components of a new service delivery system for Illinois' citizens with developmental disabilities, including the elements of services, the protection of rights and the procedures and standards that would be required to institute such a service system. The 1989 legislation also anticipated the possible need for further legislation to implement the service plan recommended by the advisory committee, including the prospect that such legislation might establish a statutory right or entitlement to certain "core" services.

The 22-member Advisory Committee was appointed by Governor James Thompson in November, 1989. Over the past year, the Committee has met on a number of occasions and developed a series of "service principles" which are intended to provide the basic framework around which a more detailed service plan can be constructed. In addition, a series of work groups have formulated a variety of more specific recommendations regarding particular components of the service plan for consideration by the full Advisory Committee. The "service principles" agreed to by the so-called H.B. 69 Advisory Committee, plus the key recommendations of its various work groups, have recently been pulled together in a draft report entitled, "The Executive Summary of the Implementation Plan Recommended by the H.B. 69 (Public Act 86-921) Advisory Committee". At the time this report was being prepared, the executive summary was being circulated for comments.

The next stage in the process will involve the preparation of an "Interagency Strategic Plan", which includes:

"1. A common philosophical and value base for all state services and planning.

2. A basis for avoiding/alleviating duplication of services.

3. A basis for the development of common training initiatives.

4. A basis for the development of a common statewide information and data base.

5. A basis for the development of common interagency consumer assessment and functional categorization.

6. A basis for the development of common interagency geographic boundaries.

7. A basis for the development of a common interagency life span case coordination system.

8. A basis for the development of an interagency implementation strategy for significant legislation.

9. A basis for the development of state office complexes, at the community level, to facilitate "one stop shopping".

10. A basis for a single, interagency, consumer based planning and advisory body with subgroups for each state agency."[1]

Under the provisions of P.A. 86-921, the Illinois Planning Council on Developmental Disabilities is responsible for coordinating the activities of the Advisory Committee. The Council also will take the lead in preparing the forthcoming "Interagency Strategic Plan". Because of "... the critical need to maximize the impact of existing generic and specialized resources through interagency collaboration and cooperation, especially in these times of dwindling federal funds and a constrained state budget", one key element of this planning initiative will be to identify new and underutilized sources of federal support for services to persons with developmental disabilities that are consistent with the principles espoused by the Advisory Committee.

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[1]"The Executive Summary of the Implementation Plan Recommended by the H.B. 69 (Public Act 86-921) Advisory Committee," November, 1990 (Draft), pp 44-42.

## II. THE PURPOSE OF THE REPORT

The purpose of the present report is to critically examine possible steps the State of Illinois might take to expand the availability of Medicaid support for services to persons with developmental disabilities in ways that are compatible with the Advisory Committee's service delivery principles. This analysis is one of a series of "white papers" the Council plans to commission as a prelude to developing " ... a prioritized implementation plan for services and the [articulation of a new] service delivery [system] for citizens with developmental disabilities."[2]

This report was prepared by the staff of the National Association of State Mental Retardation Program Directors, under a contractual agreement with the Illinois Planning Council on Developmental Disabilities and the Illinois Department of Mental Health and Developmental Disabilities. NASMRPD was asked to undertake this analysis of current and potential future uses of Medicaid dollars in Illinois because of the staff's extensive knowledge of relevant federal Medicaid policies as well as the various ways in which other states have used Title XIX financing to expand and improve services to persons with developmental disabilities.

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[2]Ibid, p. 41.

## III. CURRENT UTILIZATION OF MEDICAID TO FUND DEVELOPMENTAL DISABILITIES SERVICES

According to Braddock et. al., Illinois received approximately $122.3 million in federal assistance from all sources during FY 1988 to help support institutional and community-based services to persons with developmental disabilities.[3] This amount represented 29.7 percent of total State expenditures for such services during FY 1988 ($405.8 million).

In recent years, Illinois has been less reliant on federal aid to finance developmental disabilities services than most other states. In FY 1988, for example, 20.1 percent of community DD services in Illinois were supported with federal dollars, while the comparable figure for institutional services was 39.1 percent. During that same fiscal year, the median federal support level for all states was 25.5 percent in the case of community DD services and 43.1 percent in the case of institutional services. **Had Illinois been at the national median support level during FY 1988, the State would have received almost $30 million dollars in additional federal assistance, which could have been used to finance needed expansions in services and/or to cushion the impact on state funding sources.**

Table 1 compares the percentage of the total cost of institutional and community-based services that Illinois and a number of other Midwestern states recovered from federal funding sources in FY 1988. As this analysis indicates, Illinois ranked seventh among the ten Midwestern states in the percentage of total community expenditures derived from federal sources, eighth in the percentage of institutional reimbursements and eighth overall. While it is true that the other states included in this analysis have marginally higher Medical Assistance matching ratios than Illinois (and, therefore, all other factors being equal, could be expected to achieve a higher percentage of federal financial participation), nonetheless there are sound reasons to believe that the State could have generated additional federal revenues had it adopted a more assertive, pro-active, interagency strategy for obtaining federal assistance. It is also worth noting that Illinois, like most other states, has come to rely on the federal-state Medicaid program as its principal source of federal assistance in recent years. Between FY 1978 and FY 1988, the proportion of total State outlays for DD institutional services derived from federal Medicaid payments increased from 19.8 percent to 36.4 percent, while Medicaid reimbursements for community DD services jumped from zero to 16.0 percent of the State's expenditures. By FY 1988, Medicaid was the source of nine out of every ten dollars which the State of

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[3]Braddock, David, et.al., The State of the State's in Developmental Disabilities; Paul H. Brookes, Baltimore, 1990.

Illinois received from the federal government for developmental disabilities services. This noteworthy shift toward greater reliance on Medicaid as a source of funding for both institutional and community-based services is in line with the experiences of most other states. Braddock's analysis of the FY 1988 budgets of the fifty state MR/DD agencies indicates that, in aggregate, 89.3 percent of the funds states received for DD institutional and community-based services that fiscal year were traceable to federal Medicaid reimbursements.[4]

While an explanation of the states growing reliance on Medicaid as a means of financing services to persons with developmental disabilities is beyond the scope of this report, suffice it to say for present purposes that there is every reason to believe that this trend will continue for the foreseeable future. Under the circumstances, the Council's decision to single out Medicaid for special scrutiny, as part of its examination of the future organization and financing of services to persons with developmental disabilities in the State of Illinois, is quite understandable. To paraphrase Willie Sutton's immortal phase: Medicaid is "where the money is".

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[4]Ibid.

# CURRENT UTILIZATION OF MEDICAID TO FUND DEVELOPMENTAL DISABILITIES SERVICES

## TABLE I

A Comparison of Federal Support for Community and Institutional Services on Behalf of Persons with Developmental Disabilities Selected Midwestern States: FY 1988*

(in percent)

| State | Community | | | Institutional | | | Total | | |
|---|---|---|---|---|---|---|---|---|---|
| | State/Local | Federal | Rank | State/Local | Federal | Rank | State/Local | Federal | Rank |
| Illinois | 80.8% | 20.1% (16.0) | 7 | 60.9% | 39.1% (35.5) | 8 | 70.3% | 29.7% (26.3) | 8 |
| Indiana | 50.2 | 49.8 (28.0) | 1 | 65.5 | 34.5 (34.5) | 10 | 57.9 | 42.1 (31.3) | 4 |
| Iowa | 71.8 | 27.2 (2.0) | 5 | 34.8 | 65.2 (61.0) | 1 | 55.5 | 44.5 (27.8) | 3 |
| Kansas | 61.0 | 39.0 (9.3) | 3 | 51.8 | 48.2 (43.3) | 6 | 55.0 | 45.0 (31.5) | 2 |
| Michigan | 72.4 | 27.5 (25.9) | 4 | 43.3 | 56.6 (56.1) | 3 | 65.8 | 34.1 (32.7) | 6 |
| Minnesota | 56.7 | 43.2 (34.0) | 2 | 39.9 | 61.1 (61.1) | 2 | 50.5 | 49.4 (43.4) | 1 |
| Missouri | 83.1 | 17.0 (8.7) | 8 | 62.4 | 37.6 (37.1) | 9 | 71.8 | 28.2 (24.2) | 9 |
| Nebraska | 73.7 | 26.3 (9.2) | 6 | 43.7 | 56.3 (56.3) | 4 | 63.7 | 36.3 (24.9) | 5 |
| Ohio | 84.2 | 15.7 (9.6) | 9 | 55.0 | 44.9 (44.5) | 7 | 74.1 | 25.8 (21.7) | 10 |
| Wisconsin | 88.0 | 12.0 (5.0) | 10 | 47.1 | 52.9 (52.6) | 5 | 68.9 | 31.1 (27.2) | 7 |

* Percentage of federal Medicaid expenditures in parenthesis.

## IV. THE POLICYMAKING CONTEXT IN ILLINOIS

Until the mid-1980s, large congregate care facilities -- i.e., State-operated developmental centers and privately-operated ICF/MR facilities with 16 or more beds -- were virtually the only recipients of Medicaid funding in the State of Illinois. Even in this area, Illinois, until fairly recently, trailed considerably behind many other states in the percentage of institutional costs recovered through federal Medicaid reimbursements. For example, it was not until FY 1982 that the State's Title XIX receipts on behalf of developmental center residents exceeded 25 percent of the total cost of operating such facilities. Meanwhile, during that same fiscal year, New York and Michigan (both of which, at the time, had Medicaid matching ratios identical to Illinois) were consistently recovering in excess of 50 percent or more of their state facility operating costs through federal Medicaid reimbursements.

With respect to community-based services, until the early 1980s Title XX social services grants were practically the sole source of federal assistance for such services in Illinois. In FY 1981, for example, the State channelled $31.2 million of its Title XX allotment to the Department of Mental Health and Developmental Disabilities to offset the cost of state-support for community DD services (which totalled $72.7 million that year). After the enactment by Congress of the Social Services Block Grant Program and the accompanying sharp reduction in the level of federal Title XX aid in 1981 (as part of the so-called "Reagan revolution"), State policymakers decided to withdraw virtually all federal Title XX dollars from community DD services and direct such funds to other purposes. One of the rationales for this action was that a concerted effort should be made to qualify community DD programs for open-ended federal assistance through the State's Medicaid program (i.e., through an organized statewide effort to certify community-based ICF/MRs, claim reimbursement for services under the "clinic services" option of Medicaid, etc.), while shifting the State's finite allocation of Title XX dollars to other welfare programs that were much less likely to qualify for Medicaid reimbursements.

In fact, however, despite a rather extensive planning and promotional effort during the early 1980s, Illinois did not begin to recover any substantial amount of federal Medicaid revenues for community DD programs until 1986. Of the $418.7 million the State expended on community DD services between FY 1982 through FY 1985, for example, only $6.1 million (or a little over one percent) was recovered from federal Medicaid payments.

Medicaid began to assume a somewhat larger role in the financing of community DD services during the later half of the 1980s for three reasons. First, after an unusually long gestation period, the initiative to certify small, community-based residences as ICF/MR

providers (which started in the early 1980s) began to take hold. As more local provider agencies came to recognize that ICF/MR, for all practical purposes, was the only viable means of financing a community residence in Illinois, especially for individuals with more extensive service needs, the number of such certified facilities began to accelerate and along with it the total Medicaid receipts for community services. Aggregate federal ICF/MR receipts on behalf of residents of community ICF/MR facilities grew from $495,400 in FY 1984 to $9.7 million by FY 1988.[5]

Meanwhile, in 1983 the State requested and received approval from the federal government to operate a Medicaid home and community-based waiver program for persons with developmental disabilities. By FY 1988, Illinois was receiving $6.7 million in federal Medicaid reimbursements on behalf of participants in the State's DD waiver program.[6]

The final factor which led to increased Medicaid receipts for community DD services was the decision in 1986 to begin claiming Medicaid reimbursement for "developmental training" services on behalf of nursing facility and ICF/DD residents who were attending day programs in the community or receiving enhanced training services on-site. This decision was prompted by a review of nursing home residents with mental retardation, conducted by the Region V Office of HCFA in 1985. HCFA officials found that several thousand persons with developmental disabilities were residing in Medicaid-certified nursing homes who had little or no access to habilitation services. As a result of this decision, the federal share of developmental training costs grew from zero in FY 1985 to $14.4 million by FY 1988.[7]

Despite the recent enhancements in federal Medicaid receipts for certain types of community DD services, Illinois, as noted above, still trails considerably behind many other states in this area of policy. New York and Michigan, both of which have Medicaid matching ratios roughly similar to Illinois, retrieved over one-quarter of total state-local outlays for community DD services from federal Medicaid reimbursements, compared to Illinois' 16.0 percent. Several smaller states recovered an even higher percentage of their community DD costs from federal Medicaid payments (e.g., South Dakota - 48.1%; Maine - 52.5%; and Rhode Island -38.0%).[8]

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[5]Ibid.

[6]Ibid.

[7]Ibid.

[8]Ibid.

Interstate comparisons such as these, however, are merely suggestive of the general extent to which a particular state (in this case Illinois) is taking advantage of federal assistance programs. Because each state's MR/DD service delivery system has evolved along its own individual lines and, consequently, faces, to one degree or another, its own unique set of issues and challenges, it is a mistake to assume that all states should strive to achieve some externally defined standard of total systemwide costs that are recovered through federal Medicaid payments. **On the contrary, instead of focusing on ways of maximizing federal revenues, a state should begin by defining the specific programmatic objectives that it wishes to achieve on behalf of identified subpopulations of people with developmental disabilities and then -- and only then -- begin to explore possible approaches to generating enhanced federal revenues THAT ARE CONSISTENT WITH THE STATE'S PROGRAMMATIC OBJECTIVES.**

Too often states seek to increase federal payments for the wrong reasons -- e.g., to offset actual or projected shortfalls in state and local revenues that will undermine the state's capacity to maintain existing programs or meet other essential public obligations. While obviously there are times when such revenue enhancement exercises are unavoidable, more than one state has learned that, when the exclusive aim is to maximize federal revenues, actions often are taken which the state later comes to regret. For example, several states which financed the initiation and expansion of community residential services almost exclusively through the ICF/MR program during the 1970s and 1980s (e.g., MN and NY) have discovered that the rapidly escalating cost of maintaining such a network of resource-intensive provider agencies can serve as a major barrier to developing less restrictive, more appropriate and more economical residential and supportive services for the growing population of people who require specially tailored living arrangements.

Fortunately, in the case of Illinois, the H.B. 69 Advisory Committee, quite wisely, has chosen to begin by establishing a set of basic principles to guide decisions regarding the expansion and improvement of services to persons with developmental disabilities. In addition, as a result of the passage and subsequent implementation of State legislation authorizing and funding the Community Integrated Living Arrangements (CILA) program, the Family Assistance (FA) program and the Home-Based Support Services (HBSS) program, Illinois within the past two years has adopted major new service delivery directions that place the State at the forefront of present, state-of-the-art thinking in the field of developmental disabilities. These new programmatic thrusts offer an immediate, practical framework for operationalizing many of the Advisory Committee's principles. The present report on possible future uses of Medicaid dollars to support DD services, therefore, begins with the premise that any new federal funding applications should be closely linked to the Advisory Committee's principles and

consistent with the philosophy underlying the CILA, FA and HBSS programs. Primary attention, therefore, will be devoted to ways in which Medicaid dollars might be used more effectively and efficiently to buttress the communization strategy that is currently being pursued in Illinois.

One central lesson that can be drawn from the states' collective experiences over the past two decades with Medicaid funding of services to persons with developmental disabilities is that the ability to access and effectively use federal entitlement dollars is closely tied to the general manner in which a state is organized to finance and deliver services. Where responsibility and accountability for managing Medicaid dollars is divided among several, autonomous state agencies, each with its own unique statutory mission, goals and operational imperatives, it is far more difficult to develop and implement a holistic strategy that takes full advantage of the financing opportunities presented by the Medicaid program, without compromising the basic programmatic directions which state policymakers have elected to pursue on behalf of the DD population.

Compared to other states which have been considerably more successful in using Medicaid dollars to support institutional and, particularly, community-based DD services, Illinois has a far more fragmented process of determining how Title XIX funds ought to be used on behalf of this population. The experiences of other states as well as the past track record of Illinois in utilizing Medicaid funds on behalf of persons with developmental disabilities strongly suggests that any comprehensive attempt to use Title XIX dollars more extensively should include an in-depth examination of possible approaches to consolidating administrative responsibility for managing Medicaid on behalf of this population. The following section of this report contains several illustrations of the ways in which the State's existing interagency decisionmaking structure has tended to thwart the effective utilization of Medicaid on behalf of persons with developmental disabilities.

## V. THE IMPLICATIONS OF CURRENT MEDICAID FINANCING POLICIES

The manner in which a state elects to use Medicaid dollars as part of its overall strategy for financing services to persons with developmental disabilities is, of necessity, influenced by a variety of economic, political and historical considerations. As a result, each state must examine the dynamics of the situation it faces before determining the most advantageous methods of utilizing financial assistance available through the federal-state Medicaid program.

The purpose of this section of the report is to identify current federal Medicaid policy options and issues that will have particular relevance to the development of a forward-looking strategy for financing community DD services in the State of Illinois. While NASMRPD's principal aim is to highlight ways in which the State might increase Medicaid support for selected types of community MR/DD services, including a brief assessment of any associated risks and potential pitfalls, an effort also will be made to point out present or emerging federal policy initiatives that could jeopardize the State's existing Medicaid funding base.

### A. Intermediate Care Facilities for the Mentally Retarded

Despite the growing tendency on the part of the states during the 1980s to emphasize alternative approaches to accessing federal Medicaid dollars on behalf of persons with developmental disabilities (especially through the HCB waiver program), as of 1988 nearly eight out of every ten Medicaid dollars (77.7%) that were expended on long term care services for this population nationally were channeled through the ICF/MR program. In Illinois, the ratio of ICF/MR to total Medicaid outlays on behalf of the DD population was only slightly lower than the national average (76.3%). Under the circumstances, it would be terribly shortsighted of Illinois (as well as other states) to overlook the need for a pro-active strategy for assuring ongoing compliance with federal ICF/MR standards, as it develops an overall plan for financing services to individuals with developmental disabilities - even if the State elects to rely principally on other forms of Medicaid financing to support the further expansion and improvement of DD services, statewide.

In its guiding principles, the H.B. 69 Advisory Committee stresses the importance of financing living arrangements that are tailored to each individual's needs and afford participants maximum opportunities for independence and integration into the life of the surrounding community. The logical corollary of this new programmatic emphasis is that ICF/MR-certified settings increasingly will be used only in those limited circumstances where specialized services and supervision are essential to the health

and safety of the facility's residents. Nonetheless, as the threatened loss of ICF/MR certification at Howe Development Center earlier this year illustrates, a passive approach to maintaining compliance with federal standards governing the operation of ICF/MR-certified facilities can cause major disruptions in even the best laid community expansion plans. In this particular instance, DMHDD officials were able to rectify the cited deficiencies and maintain the facility's certification by reallocating dollars from other State developmental centers and reducing the Howe census through selected inter-facility transfers and placements. However, it is not hard to envision a situation in which the unanticipated costs of shoring up a large, non-compliant public or private ICF/MR could drain off resources that otherwise would be available to support enhancements in community DD services. Indeed, this very situation already has occurred in a number of states.

The difficulty a state faces in structuring a plan to assure ongoing compliance with federal ICF/MR policies is that recent modifications in such policies, as contained in the revised, 1988 "conditions of participation" (53 CFR 20447) and accompanying guidelines and interpretations, elevate the uncertainties involved. The modifications incorporated in the 1988 revisions to federal ICF/MR rules are too numerous to mention in this brief overview of federal policy issues. Two specific features of these revised policies, however, deserve to be highlighted for present purposes:

- The open-ended definition of active treatment. The definition of active treatment contained in the June 4, 1988 ICF/MR conditions of participation (COP) is extremely broad and, consequently, places a considerable amount of discretion in the hands of federal and state surveyors who are charged with determining whether a facility is in compliance with this key regulatory requirement. This is not a new problem, since certified facilities have been required to provide active treatment ever since the original federal standards were issued in 1974. The revised COPs, however, clarify federal expectations regarding compliance with this keystone standard and assign much higher priority to ascertaining whether a facility is meeting such expectations. It can be argued that, as both surveyors and facility managers gain more experience in conducting and responding to ICF/MR surveys, a tacit understanding will be reached concerning the levels of performance which represent substantial compliance with the active treatment provisions of HCFA's rules. NASMRPD, however, continues to receive reports which suggest that, in practice, determinations regarding compliance with federal active treatment requirements vary considerably from one survey team to another. Given the millions of dollars of federal reimbursement that often hinge on such certification decisions, nagging uncertainties about the real operational test of compliance remain.

Last year, HCFA established a special internal/external work group

to study this area of policy and see if it were feasible to develop better operational criteria for determining the presence or absence of active treatment services. Thus far, the work group (which includes NASMRPD representatives) has reached no conclusions. At this point, however, it seems unlikely that any recommendations that do emerge from the work group (or any related policy clarifications issued by HCFA) will eliminate the ambiguities associated with this inherently subjective area of compliance reviews.

It is difficult, even under the most favorable circumstances, to maintain high quality services in complex, multifaceted public and private intermediate care facilities for the mentally retarded. The subjectivity associated with compliance reviews under HCFA's new ICF/MR conditions of participation -- particularly with respect to the provision of "continuous, aggressive active treatment" services -- simply compounds the vulnerability of such facilities to negative survey findings and the potential loss of certification.

As noted earlier, Illinois already has experienced the disruption and destabilization that can accompany threatened ICF/MR decertification/termination actions at Howe Developmental Center. Faced with the Hobson's choice of committing the thousands (or even millions) of additional dollars necessary to rectify cited deficiencies or losing millions of dollars in federal Medicaid reimbursements, a state has little choice but to obligate the additional dollars and deploy the enhanced staff resources necessary to retain (or re-establish) a facility's certification. **The central lesson is that any comprehensive attempt to develop a viable, long range approach to financing community-based MR/DD services must be linked to a parallel effort to ensure continued compliance with federal standards in all existing and future ICF/MR-certified facilities.**

The linkage between client eligibility and facility certification. HCFA's new regulatory definition of active treatment states explicitly that the term "...does not include services to clients who are able to function with little supervision or in the absence of [a] continuous active treatment program" (42 CFR 483.440(a)(2)). Furthermore, HCFA's guidance to federal and state surveyors makes it clear that, in instances where a facility has a significant number of relatively independent residents who, in the judgement of the survey team, do not require active treatment, the surveyors should question whether the facility can be properly classified as an ICF/MR.

In a 1989 letter to NASMRPD, the Director of HCFA's Office of Survey and Certification, Dr. Wayne Smith, noted that state ICF/MR surveyors have been instructed by HCFA to "...review whether or not priority has been given by the individual's ID team to training in

... basic skills [as required under 42 CFR 483.440(c)(6)(iii); otherwise designated as Data Tag No. 242 in HCFA's interpretive guidelines] in the absence of an individual's independent mastery of them." He went on to assert that the target population of the ICF/MR program consists of individuals with "...significant deficits in growth and development" and "to the extent that clients increasingly demonstrate that they do not need the types of services described in W242, and increasingly correspond to the characteristics of clients described in W197 [i.e., persons..."who are able to function with little supervision or in the absence of a continuous active treatment program"], such that the overall nature of the facility's services would not require it to provide active treatment, the facility will not qualify as an ICF/MR."[9]

In Illinois, it had been estimated that 35-40 percent of the population currently residing in community ICF/MR facilities with 15 or fewer beds (or 438 individuals, based on FY 1988 data) do not require round-the-clock medical supervision and could benefit from a less restrictive living arrangement.[10] While this estimate certainly is open to dispute (given the imprecise federal/state parameters of ICF/MR eligibility) and, in any event, does not provide a basis for determining how many of these individuals (as well as residents of other ICF/MRs) might be "...able to function with little supervision or in the absence of continuous active treatment...", there appears to be ample reason for the State to give high priority to identifying those ICF/MR residents with relatively well developed daily living skills and initiate actions to transfer them to alternate residential settings.

A recent report by the Illinois Chapter of the American Association on Mental Retardation recommended that: (a) 438 higher functioning individuals currently residing in small, community-based ICF/MRs be transferred to Community Integrated Living Arrangements (CILAs); (b) those individuals be replaced by a similar number of persons transferred from large, private ICF/MRs; and (c) the per diems of ICF/MRs with 15 or fewer beds be increased by five percent to compensate for the additional responsibilities associated with serving a population with more extensive service needs.[11] This

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[9]Letter to NASMRPD Executive Director Robert M. Gettings from Wayne Smith, Ph.D., Director, Office of Survey and Certification, Health Standards and Quality Bureau, Health Care Financing Administration, October 23, 1989.

[10]"Illinois Chapter AAMR Working Policy Paper on Services for Individuals with Mental Retardation and Developmental Disabilities," September 15, 1989, p. 2.

[11]"Technical Notes: Attached Table on Illinois' FY 1995 Projected Costs," Illinois Chapter of the American Association on Mental Retardation, p. 3.

recommendation appears to be consistent with the general thrust of the H.B. 69 Advisory Committee's principles; in any event, prompt action should be taken to eliminate inappropriate placements in ICF/MRs in order to avoid later federal disallowances.

Of at least equal importance, the State needs to establish a more effective process of assuring that all newly certified ICF/MRs, regardless of size, are: (a) designed to serve only those specific target populations which clearly are in need of a comprehensive, 24 hour program of care and supervision; and (b) consistent with the State's overall plan for the expansion and improvement of residential services and supports for persons with developmental disabilities, including services funded through HCB waiver programs. The existing "certificate of need" process in Illinois is largely provider driven, rather than being the product of a rational set of statewide policies regarding the specific role that privately operated ICF/MRs are expected to play in the current and future array of residential services in Illinois. The initiative in establishing additional ICF/MR bed capacity rests primarily with provider agencies. As a result, in recent years Illinois has been adding roughly 350 ICF/MR beds per year (mainly in small community residences) at an additional cost of approximately $3.2 million in state matching funds, without any clearly established procedure for weighing possible alternative methods of deploying these scarce State resources. More specifically, since the number of persons a state can serve through an approved home and community-based waiver program is tied directly to the number of individuals served in ICF/MRs, current laissez-faire procedures for establishing newly certified ICF/MRs could foreshorten the State's prospects of expanding CILA services through the HCB waiver authority (see additional discussion under V-B below).

The lack of a synchronized process for managing the certification of new ICF/MR facilities and the use of the HCB waiver authority is a prime example of the price Illinois pays for the current fragmentation in administrative responsibility for delivering and financing services to persons with developmental disabilities. The Illinois Health Facilities Planning Board (HFPB), appointed by the Governor and staffed by the Department of Public Health (DPH), is responsible for reviewing and approving applications to establish new or expanded ICF/MR facilities. Rate setting and reimbursement policies (a major determinant of the number and types of newly created facilities) are set by the Department of Public Aid, which also is responsible for certifying such facilities and conducting inspection of care reviews. The Department of Public Health (DPH) is responsible for surveying ICF/MR providers, determining whether they are in compliance with the federal COPs and recommending certification actions by DPA. The Department of Mental Health and Developmental Disabilities, meanwhile, has a very limited role in determining the number and types of ICF/MR beds to be established (other than reviewing and sharing its comments with HFPB during the CON process); conversely, DMHDD has been delegated broad

responsibility by the Legislature for overseeing the development of a statewide network of services for persons with developmental disabilities and, more specifically, handling the day-to-day administration of the current DD Medicaid waiver program (as well as the replacement DD waiver program and the new OBRA/DD waiver program that are awaiting HCFA approval). DMHDD also directly operates nine State developmental centers and DD units at five of the State's mental health centers.

It is not a question of the lack of interagency collaboration (of which there appears to be ample in Illinois), but rather that the State lacks a fixed point of administrative accountability for Medicaid financed services to persons with developmental disabilities. In the opinion of the author, it is doubtful, based on the State's past track record, that Illinois will be able to use Medicaid resources more effectively on behalf of the DD population until the administrative locus of accountability for financing and delivering services are consolidated (see additional discussion in Section VI).

B. Nursing Home Reform

The federal Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203; OBRA-87) included sweeping revisions in federal statutory requirements governing the survey, certification and operation of Medicaid-funded nursing facilities (previously referred to as intermediate care and skilled nursing facilities). Included among these requirements were specific provisions governing the placement and retention of persons with mental illness, mental retardation or related conditions in Medicaid-certified nursing facilities. These provisions can be briefly summarized as follows:

- By January 1, 1989, each state was required to establish a preadmission screening program to prevent the inappropriate placement of persons with mental illness, mental retardation and related conditions in Medicaid-certified nursing facilities, using criteria developed by the Secretary of Health and Human Services.

- By April 1, 1990, the states, using the aforementioned HHS criteria, were required to assess each nursing facility resident with mental illness, mental retardation or other related conditions to determine whether he or she required the level of services provided in a nursing facility and also whether the subject individual needed active treatment services.

- By April 1, 1990, nursing facility residents with mental retardation or other related conditions who were determined by the State to be residing inappropriately in a nursing facility had to be: (a) transferred to a more appropriate setting (if a person had been a nursing facility resident for 30 months or less); or (b) offered the choice of remaining in the facility while receiving

active treatment services or of being transferred to a more appropriate setting (if a person has been a NF resident for more than 30 months).

States were given an opportunity to request (and the Secretary to grant) an extension of the April 1, 1990 deadline for completing case dispositions by filing an "Alternative Disposition Plan (ADP). Congressional action in 1988 extended the deadline for approval of such plans from October 1, 1988 to April 1, 1989. Last year, forty-five states (including Illinois) submitted and received HCFA approval of an ADP.

These provisions were adopted by Congress in an effort to halt the inappropriate admission of persons with developmental disabilities (and mental illness) to nursing facilities and to force states to develop alternative placements/services for persons found to be residing inappropriately in nursing facilities.

Illinois' ADP was approved in March, 1989, along with the plans of most other states. Unlike other states, however, Illinois had previously entered into an agreement with the Chicago Regional Office of HCFA in October, 1987 to eliminate inappropriate nursing home placements involving persons with developmental disabilities (but not mental illness). This earlier plan was an outgrowth of a review conducted by HCFA Region V officials in 1985, which concluded that there were several thousand (later estimated as 3,000) persons with mental retardation and related developmental disorders residing in Medicaid-certified nursing homes who needed but were not receiving specialized developmental training services.

The State's ADP calls for using several strategies to improve services to inappropriately served nursing facility residents with developmental disabilities, including:

- establishing a statewide network of Pre-Admission Screening (PAS) agents to: (a) screen all applicants for admission to Medicaid-certified nursing facilities, after January 1, 1989, and determine whether such placements are appropriate in the case of persons known or suspected of being mentally ill or mentally retarded; and (b) reviewing all current NF residents with an "MI or MR/DD" diagnosis and determining the appropriate disposition in each such case.

- transferring up to 400 NF residents to private ICF/MR facilities as residents of these latter facilities are moved into less restrictive community settings through the State's regular DD waiver program;

- transferring up to 1,950 NF residents directly into community residential settings (mainly as part of the new Community Integrated Living Arrangements program) over a three year period.

These transfers are to be financed through a specialized NF waiver request, which the State has submitted to HCFA.

- extending developmental training and other active treatment services to an estimated 600 individuals who choose to remain NF residents.

It is important to point out that the actual mix of service/placement options outlined in the State's ADP was highly tentative, since at the time the plan was prepared Illinois officials had no way of predicting the number of affected individuals who would: (a) choose to remain NF residents; or (b) the types of placement alternatives that might be selected by those who did elect to be transferred out of NFs. Illinois' ADP, however, does offer useful insights into the perceptions of State officials regarding the most desired residential outcomes (i.e., the plan's heavy emphasis on using the CILA model to serve this population).

Although not explicitly mentioned in the State's ADP, another integral part of Illinois' strategy for responding to inappropriate nursing facility placements is to convert 18 SNF/Pediatric facilities, with a total bed capacity of 1,135, into ICF/MRs. For the past year, DPA officials have been attempting to implement this portion of the plan by: (a) arranging, in cooperation with the staff of the Department of Public Health (DPH), training sessions on active treatment programming and other key features of the federal ICF/MR standards for the staff of the affected facilities; (b) arranging for DPH survey teams to conduct mock surveys in these facilities; and (c) helping the facilities to make physical plant modifications necessary to comply with federal standards (mainly related to the so-called 4-to-a-bedroom rule).

In comparison to most other states, Illinois faces a much more daunting challenge in attempting to comply with the so-called PASARR requirements of OBRA-87. To the considerable credit of DPA and DMHDD officials, this challenge has been met in a forthright manner and substantial progress has been made to date in implementing the State's compliance plan. Nonetheless, numerous problems still must be resolved if the State is to meet the compliance deadline specified in its ADP (June 30, 1992). Among the most pressing problems are:

- The State has yet to institute a fully reliable data system for monitoring the status of PASARR compliance efforts, statewide.

- PAS agents have completed the initial round of annual NF resident reviews and reported their findings/recommendations, but have not received, in most instances, written indication of the resident's choice (i.e., to remain in a NF or to be transferred to an alternative setting). Data on resident choice will have a major

bearing on the State future plans since: (a) current placement plans are based on rough "guessimates" of the number of residents who might choose to be transferred; and (b) a high proportion of the affected NF populations have the right, under the terms of P.L. 100-203, to remain in a nursing facility if they so choose (because they have resided in a NF for 30 months or more). One of the difficulties the State faces in implementing the resident choice process is how to obtain the informed consent of NF residents who are of questionable competency, especially in the numerous cases where there is no next of kin to act on the resident's behalf.

The State has encountered unexpected delays in gaining federal approval of its DD replacement waiver request as well as its OBRA/DD waiver request (see further discussion under V-C below). While placements out of nursing facilities have proceeded in the absence of the projected waiver-financing, the State thus far has had to forego federal Medicaid assistance in financing residential alternatives for such former NF residents.

DPA officials now project that at least five of the original 12 private SNF/Pediatric facilities that were targeted for conversion to ICF/MRs will not meet the State-imposed deadline of December 31 of this year. [N.B., DPA has informed all 12 facilities that unless they convert by the above date, they will revert to a general NF certification status and, therefore, qualify for a lower monthly, per capita payment rate.] In addition, a sixth SNF/Pediatric facility was in the process of being totally decertified as a provider of Medicaid services during the author's recent visit to Illinois. Assuming that efforts to convert these SNF/Ped facilities are unsuccessful, the State will have to find other placement alternatives for the residents of these facilities, thus placing even further pressure on a service system that is already pressed to the limits.

Looking beyond the immediate problems associated with implementing the State's ADP by June 30, 1992, the State has to be wary that near term solutions do not lead to future problems. For example, the decision to convert SNF/Ped facilities to ICF/MR certification status may have been an unavoidable step given the other pressures the State's DD service delivery network faces. Nonetheless, the possibility exists that, through these conversions, the State might be inviting future ICF/MR compliance problems. At least the experiences of other states with similar types of conversions is not particularly promising. Michigan, which is currently in the process of closing a network of specialized nursing facilities for persons with mental retardation that was created in the early 1970s, is an excellent case example.

C. <u>The Home and Community-Based Waiver Authority</u>

Illinois initially received federal approval to operate a Medicaid

home and community-based waiver program on behalf of a target population with developmental disabilities in 1983. At the time, the primary justification for the program was to assist the State in moving residents of publicly-operated developmental centers to less restrictive settings. Initially, the State emphasized the direct placement of DD and (to a lesser extent) private ICF/MR residents into waiver-financed Community Residential Alternatives (CRAs; i.e., group homes with a maximum of 8 beds) as well as other community residential settings.

In 1987, the State's DD waiver program was replaced by a new, revised program, covering an additional three year period and increasing the ceiling on the total number of recipients of services from approximately 600 in the third year of the initial waiver period to 1,500 in the third year of the new waiver period. In addition, the 1987 replacement waiver was intended to increase the proportion of waiver diversions (i.e., versus deinstitutionalized participants) from approximately 30:70 to 50:50.

Due in large part to the fact that the Illinois Legislature appropriates funds for HCB waiver services as part of the budget of the Department of Mental Health and Developmental Disabilities and then treats federal reimbursements for such services as revenue to the State when received (in the budget of the Department of Public Aid), Illinois has never served more than 725 individuals in its DD waiver program, even though it actually had authority from the federal government to serve up to 1,500 waiver recipients. [N.B., In 1989, Illinois asked HCFA for authority to amend its DD waiver request in order to voluntarily scale back the maximum number of participants in the third year of the waiver period from 1,500 to 730; this request was approved by HCFA early in 1990.]

The decision to request a reduction in the maximum number of participants in the DD waiver program was a direct outgrowth of the fact that the Legislature failed to appropriate sufficient funds in FY 1986-87 through FY 1988-89 to expand waiver services to the caseload limits specified in the State's 1987 waiver request. Eventually, DPA and DMHDD officials concluded that it would be necessary to adjust the ceilings on waiver participation and expenditures in order to reconcile the State's estimates with: (a) actual utilization and cost data reported to HCFA during year two of the program; and (b) the assumptions used to derive estimates for year one of a proposed new, replacement waiver request.

In 1988, however, the Illinois Legislature enacted a bill establishing the Community Integrated Living Arrangement (CILA) program and appropriated initial funds to launch this new program. CILA funding was substantially increased in FY 1989-90 and FY 1990-91, primarily in order to transfer inappropriately placed residents with developmental disabilities out of Medicaid-certified nursing facilities, thus implementing the State's plan to come into

compliance with the requirements of federal Medicaid law as added by OBRA-87. As of July 1, 1990, a total of 918 individuals were receiving services through the CILA program and a total of $34.8 million in funds had been allocated among eligible community agencies to serve up to 1,525 CILA participants by the end of the current fiscal year.

Officials of DMHDD and DPA deserve considerable credit for recognizing the potential for linking HCB waiver financing to the planned expansion of CILA services. Indeed, the waiver "renewal" request submitted by the State in October, 1989 (to replace the State's existing DD waiver program, which was due to expire in March, 1990) was designed to shift the emphasis of the State's waiver program to CILA-type services and expand the total number of persons eligible for waiver-supported services from a maximum of 730 to 3,200 by the third year of the new waiver period. Of the total number of waiver recipients, approximately 70 percent were to be served through the CILA program.

Simultaneously, the State also submitted a separate waiver request to serve inappropriately placed nursing facility residents with developmental disabilities. Participation in this second DD waiver program was projected to grow from 840 participants during the first year to 1,950 by the third and concluding year of the waiver period. Here again, the centerpiece of this so-called OBRA waiver was to be the provision of CILA services, with 65 percent of waiver recipients scheduled to be served through the CILA program.

Fourteen months have passed since the State's two new DD waiver requests were submitted to HCFA. In the meantime, HCFA has extended the expiration date of the existing DD waiver program by 90 days on several occasions, pending final action on a replacement request.

Quite clearly, the State of Illinois would have received substantially more federal assistance through the HCB waiver authority this fiscal year and last had the State's "renewal" and OBRA waiver requests been approved and implemented in accordance with the original schedule (i.e., as of March 1, 1990). As it turned out, CILA placements have been funded with State general revenues on behalf of hundred of program participants who otherwise would have qualified the State for federal Medicaid cost sharing.

The question that needs to be asked is: why has final federal action on these two pending DD waiver requests been delayed for so long? Two explanations might be offered. The most straightforward answer is that the State thus far has been unable to satisfy all of the conditions HCFA has established for approval of these requests. Initially, HCFA objected to the State's plan to use a "wrap-around" rate to pay for case management, day habilitation and residential support services on behalf of CILA participants, in order to allow community provider agencies maximum flexibility in serving waiver

program participants. Another major impediment to approval of these two waiver requests was that the State had not promulgated final regulations governing the provisions of either day training services or CILA services and HCFA refused to approve the State's requests until these rules were issued in final form. Because of the complexities of Illinois' rulemaking procedures, the publication of final CILA and day training regulations took almost a year, but eventually they were issued in September of this year. Finally, HCFA has expressed skepticism about the State's proposal to sharply increase the rate of participation in the State replacement waiver program (from approximately 725 at present to 1,550 during the first year of the new program and eventually to 3,200 by the third and final year of the program), arguing that this rate of growth is not justified in terms of the ICF/MR bed capacity that would be available in the absence of the proposed waiver program. Although DPA and DMHDD officials have furnished HCFA with additional documentation to justify the original request, as of this writing an agreement on utilization and expenditure levels under the proposed replacement waiver program has not been reached with HCFA.

All of the above explanations for the delay in obtaining approval of the pending waiver requests are quite typical of the problems that states encounter in negotiating waiver agreements with HCFA. Certainly, there are numerous examples of situations where HCFA has delayed approval of a state's waiver request -- sometimes for many months -- over issues which seemingly are far removed from the substantive merits of the state's proposal.

Still, one must wonder whether it would not have been possible to obtain approval of these waiver requests if the State had assumed a more pro-active stance in its negotiations with HCFA. Certainly other states have managed to settle equally serious differences with HCFA officials in far less time. The question, therefore, remains: why has it taken so long to gain federal approval of these two waiver requests.

One plausible explanation is that no agency of Illinois state government has a "life or death" interest in gaining approval of the subject waiver requests because agency appropriation levels are not tied to the projected revenue that would be generated through these new programs. Had, for example, the two waivers been approved ten months ago, the amount appropriated for nursing facility placements, state developmental center transfers and diversions, etc., in the budget of the DMHDD, would have been no greater, so DMHDD officials have had little incentive to ensure that negotiations with HCFA are brought to a satisfactory and speedy conclusion. Similarly, had federal waiver reimbursements been increased as a result of the earlier approval of these waiver requests, the level of budgeted activities of DPA would not have changed; the Department simply would have been the conduit for channeling additional federal revenues to the State Treasury. Here

again, where no single agency of State government is held directly accountable for assuring that federal Medicaid funds are received and given the tools necessary to see that these objectives are met in a timely fashion, the overall financial interests of the state often become a secondary consideration in the day-to-day management of agency activities. As one DMHDD official observed during the interviews that were conducted prior to preparing this report, "we [DMHDD] receive no credit for generating additional Medicaid revenues for the State. It just goes back into the general fund."

The principal reason why State officials have not pressed HCFA to approve the pending waiver requests is that there are no existing procedures for filing and processing CILA reimbursement claims through DPA's Medicaid Management Information System (MMIS) and, therefore, the State is not in a position to collect FFP for expanded waiver services, even if the two pending requests were to be approved. Commitments to develop a new MMIS billing system for DD waiver services date back to 1985; but, it was not until earlier this year that DPA officials promised to have in place a MMIS compatible billing system for CILA and other waiver-financed DD services by June, 1991. This system, once it is available, will have the capability to not only generate accurate, up-to-date client and cost reports but also to transpose such data into Title XIX reimbursable claims that can be processed through DPA's regular MMIS for purposes of recovering federal Medicaid payments.

The lengthy delays in developing a Medicaid-compatible data reporting/claims processing system is symptomatic of the more general problem facing the State's developmental disabilities service delivery system -- i.e., the lack of a coherent approach to managing DD services at the state and sub-state level. The absence of such a data system has had no immediate negative ramifications for any of the key system actors. As pointed out earlier, DMHDD and DPA realize few, if any, direct benefits from drawing down additional FFP since their budgets are fixed by legislative appropriations. Thus, while administratively high priority may be assigned to establishing a new data reporting system that can support an expanded/revised array of DD waiver services, neither agency loses in the short run if delays are encountered in putting such a system into place.

Furthermore, local agencies that furnish services which are potentially reimbursable through the HCB waiver authority receive their funding in advance from DHMDD and, consequently, have little incentive to press for a new data reporting system that is MMIS-compatible. Indeed, Medicaid-driven reporting requirements frequently are viewed by provider agencies as unnecessary and time-consuming red tape that restrict the latitude of an agency to properly respond to the needs of the people it serves. They realize that a new Medicaid reporting system -- irrespective of its merits as a statewide management tool -- inevitably will involve greater accountability and considerably more administrative work on

their part.

Finally, there may be a temptation to write off the delays in implementing the new DD replacement and OBRA waiver programs to administrative foot-dragging or incompetence. Such an explanation strikes this observer as an oversimplified and inaccurate assessment of the current situation in Illinois. Indeed, the pending DD waiver proposals are as well-conceptualized and competently drafted as any state waiver proposal. The root of the problem appears to lie in the lack of a clear point of administrative accountability at the State level and a sense of urgency about the creation of the infrastructure necessary to manage waiver services effectively.

In order to obtain HCFA approval of a waiver request and, of at least equal importance, manage the program in accordance with federal statutory and administrative expectations, a state must be prepared to commit the resources necessary to achieve these ends. DMHDD, in retrospect, was not in a position to make such a commitment when the replacement and OBRA waivers were submitted in the fall of 1989. The staff of the Department's Division of Developmental Disabilities, which has primary responsibility for designing and implementing DD waiver services, also carries numerous other responsibilities. More particularly, the attention of the DD Division's staff over the past year has been focused, to a considerable extent, on implementing newly enacted State legislation establishing the Family Assistance Program and the Home-Based Support Services Program. Activities aimed at assuring prompt HCFA approval of the pending waiver requests, as a result, have had to compete with other high priority, Department-wide initiatives on behalf of persons with developmental disabilities. Again, keep in mind that early approval of these waiver proposals would not have given the Department immediate authority to expard waiver services, since legislative appropriations were not available for this purpose.

Yet, another barrier to the successful management of DD waiver services in the State of Illinois is the lack of an effective means of controlling the number of ICF/MR beds, statewide. As noted earlier in this report, responsibility for certifying and overseeing the operation of private ICF/MRs rests primarily with the Departments of Public Health (DPH) and Public Aid (DPA), while DMHDD is charged with day-to-day administration of DD waiver programs. The two pending DD waiver requests assume that the net increase in the State's overall ICF/MR bed census will grow only marginally in future years (once the previously discussed conversions of SNF/Ped facilities are completed). Given the provider-driven nature of the State's existing certificate-of-need process and the current dispersion of responsibility for managing long term care services to persons with developmental disabilities among several agencies of state government, the capacity of the State to manage the supply of ICF/MR beds within the parameters

established by the proposed waiver requests would appear to be somewhat suspect. During the course of interviews that were conducted prior to the preparation of this report, the author was told of a number of pending and forthcoming CON requests to establish new ICF/MR facilities which, if approved, seemingly could push the State over the utilization caps specified in the pending waiver proposals.

Should the State exceed the ICF/MR utilization and expenditure caps specified in the pending waiver proposals (assuming they were to be approved in their current form), continuation of these waiver programs might be jeopardized. Certainly, HCFA has regulatory authority to withdraw a state's waiver or disapprove renewal if it finds that the state has exceeded its expenditure and utilization estimates and, consequently, the subject waiver program is no longer cost-effective. For this reason, it is vital that a state establish the organizational capability of managing all Medicaid-funded long term care resources in accordance with the terms specified in its approved HCB waiver program(s).

D. Optional Case Management Services

In 1986, Congress added Section 1915(g) to the Social Security Act. This provision of the Act permits states to offer case management services on an optional basis to selected target populations of Medicaid recipients.

Among the key advantages of the Section 1915(g) state plan authority are:

- the ability to recover federal financial participation in the cost of services that already are being provided to selected groups of Medicaid recipients without violating the "comparability" and "statewideness" provisions of the Act. A fundamental underlying premise of Medicaid law is that if a state chooses to offer a particular service as part of its Title XIX program, it must provide that services to all recipients who are found to need it, regardless of where they live in the state or the particular subpopulation of recipients they may be part of (e.g., aged, blind, disabled, AFDC, etc.). In the case of targeted case management services, however, a state is not bound by the law's comparability or statewideness requirements. It may, therefore, extend such coverage only to a selected group or groups of recipients, the precise parameters of which are spelled out in the state's TCM amendment. As a result, a state can carefully weigh the fiscal and programmatic consequences of potential coverages before submitting a state plan amendment.

- the absence of any linkage to the recipient's need for institutional services. Unlike the HCB waiver authority, where a potential participant must be found in need of institutional long

term care services before he/she can be declared qualified for waiver services, any individual who is eligible for Medicaid benefits potentially may be the recipient of targeted case management services. Thus, a state may (and, indeed, a number of states already have) declared a larger number of persons eligible for TCM services than it could possible cover under a HCB waiver program.

· the authority to deliver targeted case management services to persons with developmental disabilities and mental illness through designated provider agencies without violating the recipients' freedom to choose among available service providers. In 1987, Congress amended Section 1915(g) of the Social Security Act to permit states to limit the types of providers of case management for "...eligible individuals with developmental disabilities or with chronic mental illness in order to ensure that the case managers for such individuals are capable of ensuring that such individuals receive needed services" (Section 4118(i)(1), P.L. 100-203). This amendment provided the states with explicit authority to furnish TCM services through a specified agency within a designated geographic area of the state (e.g., a community mental health center, a county or regional mental retardation/developmental disabilities agency, etc.).

· the authority to claim Medicaid reimbursement at the state's service matching ratio rather than the administrative matching ratio. Prior to the addition of Section 1915(g) to the Act, some states claimed Medicaid reimbursement for certain types of case management services as an administrative expense. The addition of Section 1915(g) not only provided the states with an explicit statutory basis for such claims, but also: (a) established a somewhat broader base for these claims, since non-administrative activities of the case manager could be covered; and (b) reimbursement could be claimed at the state's service matching ratio rather than at a flat 50 percent administrative cost ratio. The latter provision is a distinct advantage to states with high federal Medicaid matching ratios and no advantage to states with minimum (50) percent matching ratios, such as Illinois.

At last report, nineteen states had amended their Medicaid plans to cover targeted case management (TCM) services for a defined group of Medicaid recipients with developmental disabilities. [N.B., Many of these same states, as well as others, also had received approval to cover TCM services for other defined target populations of Medicaid recipients, including persons with mental illness, victims of AIDS, frail elderly individuals, medically fragile children, etc.]. Each of these states have established eligibility criteria for TCM services that are tailored to its own unique needs and circumstances.

The possibility of amending the State Medicaid plan to include

coverage of TCM services for selected subpopulations of people with developmental disabilities has been discussed in Illinois on a number of past occasions. According to persons who have been party to these discussions, the principal barrier to adopting the Section 1915(g) coverage has been and remains the lack of consensus regarding the way in which case management services should be organized and delivered, statewide. Unlike many other states, Illinois never adopted a unitary approach to furnishing case management services to persons with developmental disabilities. Whereas many other states decided to vest case management responsibilities with a single local entity (e.g., a county or regional board/agency) years ago, in Illinois a number of quite distinctive DD case management "models" have emerged over the past two decades.

DMHDD currently awards approximately $8 million annually to providers of "case coordination services" under its grant-in-aid program. The Department, however, also pays for case management as an element of service under a number of other purchase of care programs, including under the existing HCB waiver program for persons with developmental disabilities. Private ICF/MRs, of course, receive a single, all-inclusive payment rate from DPA, which is intended to cover all reimbursable service costs, including the individual habilitation planning and coordination functions of the facility's Qualified Mental Retardation Professionals (QMRPs).

At the current time, there are at least two principal schools of thought regarding the steps that need to be taken to "rationalize" the State's approach to supporting case management services. One group feels that a provider of case management service should be organizationally independent of any agency that is responsible for furnishing direct day, residential and/or support services to individuals with developmental disabilities.

A small but potentially significant step toward establishing an independent case management network was taken last year when the State agreed to create a new network of Pre-Admission Screening (PAS) agents and assign to these entities initial case management responsibility for persons with developmental disabilities and mental illness who are scheduled to be moved out of nursing facilities, in accordance with the requirements of OBRA-87. The initial aim of DMHDD officials was to choose PAS agents that were independent of any other provider of direct services to persons with mental illness or mental retardation. In the final analysis, however, only 9 of the 29 PAS agents originally selected by the Department were free-standing organizations. The remainder were either consortia of existing local service providers (4) or distinct organizational units of existing provider agencies (14). In addition, under current policies: (a) the case management responsibilities of the PAS agent ends 30 days after the individual has been placed; and (b) are limited to applicants for admission to

or recipients of DMHDD-supported **residential** services, and, as such, do not encompass the entire population receiving State-financed developmental disabilities services.

Those who are opposed to setting up a separate network of case management (or service facilitation) agencies argue that such agencies would simply add another layer or bureaucracy to the already complicated service delivery system. They would prefer to see existing policies continued, where a provider agency is permitted to furnish case management or service facilitation services to persons enrolled in its day or residential programs.

At the current time, active discussions concerning the use of the TCM coverage option on behalf of a group of persons with developmental disabilities are taking place only in the context of expanding Early and Periodic Screening, Diagnosis and Treatment eligibility/benefits (see further discussion below). The Medicaid Services Subcommittee of the Children's Health Task Force recently recommended that a multi-agency work group be formed to develop a plan for providing case management to children who are eligible for EPSDT services. In making this recommendation, the Subcommittee indicated that it "did not develop the concept [of case management services] sufficiently to recommend how it should be provided...", but noted that "case management is particularly important due to our move toward greater fragmentation of [EPSDT] screenings and services."[12]

Unlike other areas of human services, case management has been recognized as an integral part of a comprehensive DD service delivery system for many years. However, it has only been in the past few years that states have come to fully recognize the keystone role that a well-defined and staffed network of case management agencies can play in initiating and carrying major, systemwide changes in the delivery of developmental disabilities services.

E. Early and Periodic Screening, Diagnosis and Treatment

Since 1969, states have been required to furnish screening, diagnostic and treatment services to Medicaid-eligible children, in an effort to prevent serious illnesses and disabilities among youngsters living in economically disadvantaged households. Under current Medicaid regulations, a state must establish a schedule for screening all eligible children to detect a wide spectrum of possible health-related problems, including any problems in physical and mental development. In addition, for many years, states have been required to make available any appropriate

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[12]Illinois Department of Public Aid, Children's Health Task Force, Medicaid Services Subcommittee, "Proposed Recommendations," October 19, 1990, p. 3.

treatment services for eligible children that are covered under its state Medicaid plan (including any specially targeted benefits for this particular population).

As part of a series of amendments to the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) authority enacted in 1989, Congress took several potentially far-reaching steps to improve the scope and effectiveness of EPSDT services (Section 6403, OBRA-89). First, Section 1905(r) was added to the Act, effective April 1, 1990. This new provision spells out, in detail, the scope and range of services that a state must furnish under its EPSDT program. The conference report on the legislation describes these provisions as a codification of current HCFA regulations. In fact, however, Section 1905(r) contains a more rigorous set of requirements governing the operation of state EPSDT programs; in particular, states now are obligated to perform various mandatory screenings and furnish follow-up services that are not specified in current HCFA regulations. For example, Section 1905(r)(1)(B)(i) mandates that a state's EDPST program include "a comprehensive health and developmental history (including assessment of both physical and mental health development)."

Second, Congress, in effect, eliminated any latitude a state might have had in furnishing otherwise Medicaid-reimbursable services to EPSDT-eligible children. Under Section 1905(r)(5), effective April 1, 1990, a state is obligated to furnish:

> "such other necessary health care, diagnostic services, treatments, and other measures described in Section 1905(a) to correct or ameliorate defects and physical and mental illnesses and conditions discovered by screening services, whether or not such services are covered under the state plan." [N.B., Section 1905(a) of the Social Security Act lists the Medicaid-reimbursable services that a state must furnish or may elect to cover under its state plan.]

Under this provision, then, if a child is determined to need physical therapy services, for example, such services must be furnished regardless of whether a state has elected to cover PT services under its state plan or otherwise furnish such services -- on a targeted basis -- to children under its EPSDT program. Essentially, all EPSDT-eligible children (including all children under the age of 21 who are AFDC or SSI recipients, plus certain other children living in low-income households who are not receiving public assistance) have been granted special status to receive any Medicaid-reimbursable service, regardless of whether a state offers such a service under its state plan. If a state **could** offer such a service, then the service **must** be furnished to an EPSDT participant who needs it.

This change in federal policy has potentially sweeping ramifications. For example, in the past many observers suggested

that it would be advantageous for states to cover particular services (e.g. physical, occupational and speech therapies) under its EPSDT program in order to access Medicaid-financing for many types of early childhood intervention services. From a practical standpoint, however, the EPSDT program proved to be less useful as a vehicle for financing early childhood services than would seem to be possible at first blush. Few states were able to systematically access this Medicaid-financing option, even though Part H of the Education of the Handicapped Act specifies that the provision of early childhood services must be coordinated with a state's EPSDT program. In part, the problem stemmed from the fact that many state EPSDT programs did not provide particularly liberal coverages of treatment services. Section 1905(r)(5) sweeps aside all current state restrictions on coverable treatment services, hence potentially creating wider opportunities to access Medicaid financing, not only for early childhood services but also for services needed by older Title XIX-eligible children.

Section 1905(r) also permits a state to "debundle" EPSDT services, by explicitly providing that individual services can be furnished by any qualified vendor. In particular, Congress specified that "nothing in this title shall be construed as limiting providers of [EPSDT] services to providers who are qualified to provide all the items and services described...". This provision potentially gives a state greater flexibility in designating and delivering services on behalf of children with disabilities.

Finally, Congress mandated that each state furnish the Secretary of HHS with specific reports concerning EPSDT services (Section 1902(a)(43)(D) of the Social Security Act). The Secretary, in turn, is directed to establish, no later than July 1, 1990, goals for each state regarding participation by eligible children in its EPSDT program.

Illinois, for example, in past years has screened a lower percentage of EPSDT-eligible children through the Healthy Kids Program (the State's EPSDT program) than the new HHS/HCFA screening guidelines call for. DPA, therefore, has been devoting considerable attention to identifying specific steps that can be taken to ensure that EPSDT screenings reach a higher proportion of eligible youngsters. A number of actions have been taken to date, including: (a) retaining 12 outreach contractors to help identify and refer eligible children to DPA for screening; (b) issuing new screening rules that incorporate the American Academy on Pediatrics' recommended periodicity schedule; and (c) raising the payment rate for developmental screening from $3 to $15 per screen and recognizing five new alternative screening instruments.

In addition, acting through the Children's Health Task Force, DPA officials are working with officials of other interested state agencies as well as non-governmental groups to consider possible options for expanding Medicaid-reimbursable treatment services that

are made available through the Healthy Kids Program. Among the recommended new service coverages outlined in the recent report of the Task Force's Medicaid Services Subcommittee are:[13]

- Case management (see discussion above);
- Comprehensive mental health assessment;
- Mental health treatment plan development and modification;
- Psychotherapy treatment;
- Developmental disabilities assessment and evaluation;
- Individual family service plan (IFSP)/individual habilitation plan (IHP) development;
- Psychological services; and
- Developmental services [N.B., The term "developmental services" is described in the Subcommittee's report as "...learning environments and activities that promote the child's acquisition of skills in a variety of developmental areas, including cognitive processes and social interactions." The report also makes clear that such services might include providing "...families with information skills" and other tools to enhance the skill level and development of their children.]

The Subcommittee also recommended that the above services be supplied to eligible children and their families through: (1) mental health clinics and other providers of mental health services under the "clinic services" option and possibly the "rehabilitation services" option of federal Medicaid regulations (see additional discussion under V-F-2 below); (b) early intervention clinics and other providers of early intervention services under the "rehabilitative services" option of federal Medicaid regulations; and (c) schools by developing a mechanism to make local school districts providers of Healthy Kids services.

It is important to point out that the above proposals, while offering intriguing and potentially far-reaching possibilities for opening up new service options for children with disabilities, are still in the early discussion stage. A great deal more work will be required before a decision can be made to put any of these new financing arrangements into place. In a telephone interview with the author of this report, the Chairman of the Children's Health Task Force hinted at the many problems which have not yet been

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[13]Ibid, p. 3-4

resolved when he pointed out that no resolution has been found to the problem of claiming Medicaid reimbursement for many of the above-listed services when the service is not delivered under the supervision of a physician.[14]

F. Other Medicaid Coverages

Medicaid law also offers limited opportunities for a state to finance specialized long term care services and supports for persons with developmental disabilities through certain "generic" Medicaid program authorities. However, states must proceed with great care before deciding to utilize such coverage options. Each of these options involves its own unique set of potential pitfalls, but they all share one common characteristic: federal law, regulations and administrative policies neither authorize nor deny a state authority to finance specialized developmental disabilities services via these particular statutory provisions.

1. **Personal Care Services**. Federal regulations and guidelines governing the provision of Medicaid-reimbursable "personal care services" specify that such services must be: (a) prescribed by a physician; (b) supervised by a registered nurse; and (c) rendered in accordance with a treatment plan. Generally, HCFA guidelines describe personal care services as the provision of assistance to a Medicaid recipient in carrying out "activities of daily living" (e.g., bathing, grooming and feeding). These guidelines, which were promulgated in the late 1970's, are less explicit with regard to the provision of "chore"-type services, except to indicate that such services must be incidental to the principal aim of providing personal care services (see further discussion below).

Current HCFA regulations also specify that personal care services must be provided in a "recipient's home". Historically, this reference to a recipient's home, however, has not been interpreted to mean that such services cannot be furnished in a licensed/certified community residence, as long as the residence is not deemed to be an "institution"; and several states claim Medicaid reimbursement for personal care services which are rendered to residents of group homes and similar community residences serving persons with developmental disabilities (e.g., MI, NY and WV). Furthermore, the regulatory prohibition against the provision of personal care services by a family member has not prevented states from limiting this restriction to "legally responsible family members" (e.g., parents of minor children; parents of disabled adults who also are the individual's legal guardian; etc.). The legitimately of both of these practices would be placed in jeopardy should HCFA's June, 1988 revision in existing personal care regulations be issued in final form (see further discussion below).

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[14]Personal interview with Steven Spence, October 30, 1990.

The major advantage of seeking Medicaid personal care payments through a state plan option, rather than through a HCB waiver program, is that the state can avoid the caseload limitations imposed by the waiver's "cold bed" test. In other words, a recipient of personal care services does not necessarily have to be at risk of institutionalization to qualify for such services (although a number of states impose such a limitation as a cost containment measure). A state, therefore, is free to provide personal care services to as many qualified recipients as it finds to be in need of such services. Furthermore, in instances where the primary need of the individual to be served is for physical care and supervision, rather than habilitation training and other developmentally-oriented services, the personal care option offers a state a straight-forward way of capturing federal financial participation in the costs of such residential services while avoiding the problems and uncertainties that often accompany ICF/MR and HCB waiver financing.

The primary reason why many states have chosen not to extend Medicaid personal care benefits to a much broader segment of the developmental disabilities population is that such services would have to be furnished to all groups of Medicaid-eligible recipients who are in need of similar long term care services/supports (e.g., frail elderly, chronically mentally ill and physically disabled individuals); and, therefore, any fiscal advantages that a state might realize by accessing this source of Medicaid funding for persons with developmental disabilities could be more than offset by the additional state costs involved in extending such services to other long term care populations. As pointed out earlier in this report, one basic tenet of Medicaid law is that any service a state chooses to cover under its Title XIX plan must be made available to any eligible recipient who is in need of the particular service (i.e., the so-called "comparability" test under Section 1902(a)(10) of Act). A state may (and usually does) request that this test be waived in the case of HCB waiver services; but, a state must be able to demonstrate that it is abiding by the comparability rule in the case of all regular state Medicaid plan services that it chooses to cover, including personal care.

Furthermore, any state that is contemplating the addition or extension of personal care coverage must take into account the potential impact of proposed revisions in federal personal care regulations which were published by HCFA on June 27, 1988 (53 CFR 24103). Under these proposed revisions, existing rules would be amended to: (a) restrict the circumstances under which Medicaid reimbursement could be claimed for housekeeping and chore services (as opposed to direct, hands-on patient care services); more specifically, no more than one-third of all allowable personal care costs could be categorized as chore/housekeeping activities; (b) limit the types of residential settings in which personal care could be provided (i.e., either the recipient's own home or a

residence serving three or fewer persons); (c) expand somewhat the nursing supervision requirements; and (d) include an explicit definition of the term "not a member of the recipient's family".

Although over 18 months has passed since the issuance of these proposed regulations, final rules still have not been promulgated by HCFA -- and there is no indication when they might be issued. The recently passed Omnibus Budget Reconciliation Act of 1990 (P.L. 101-508) includes a provision codifying the existing regulatory definition of personal care services. This amendment was included in the Act primarily because the State of Minnesota had been challenged by HCFA for claiming Medicaid reimbursement for personal care services rendered outside the recipient's home. The final language of the amendment, however, permits coverage of personal care services outside the recipient's home only in the State of Minnesota through 1994 (after which the same option will be available to all states). Instead of offering additional protection to states that claim personal care reimbursement under Medicaid, the new statutory language may provide HCFA with further ammunition to support its contention that some states are misapplying the personal care benefit, especially states (other than Minnesota) that claim federal FFP for services rendered outside the recipient's home.

Illinois does not cover personal care services under its state Medicaid plan. Furthermore, no plans for adding this optional coverage were reported during the interview that preceded the preparation of this report.

2. **Medicaid Rehabilitation and Clinic Services**. Approximately fourteen (14) states currently claim Medicaid reimbursement for specialized daytime habilitation and training services provided to persons with developmental disabilities. These claims are filed under either the "medical rehabilitation service" state plan option (42 CFR 440.130(d)) or the "clinic services" state plan option (42 CFR 440.90). The principal advantage of electing one of these coverages is that it allows a state to capture federal reimbursement for daytime services on behalf of clients who are not receiving other Medicaid-financed long term care benefits (i.e., individuals who are not residents of an ICF/MR or participants in waiver-financed services). Because such services usually represent the second most costly component of the typical state's MR/DD service array (i.e., after residential services), many of the states which utilize these Medicaid coverages generate millions of dollars annually in federal Medicaid reimbursements.

Illinois covers both "clinic services" and "rehabilitative services" under its current Medicaid plan. Furthermore, for over two years, the State has had in place regulations authorizing the provision of mental health clinic services; but because of the heavy medical orientation of these rules, few local mental health centers have been able or willing to qualify as providers of such

services. Indeed, as of late October, 1990, the State had only four certified providers of mental health clinic services.

Last year, a Medicaid Clinic Option Advisory Committee was formed to explore possible modifications in the 1988 mental health clinic rules. The mission of the Advisory Committee was to propose ways of: (a) expanding the types of services that can be offered through community mental health centers and other DMHDD-certified community clinics for persons with mental illness; and (b) addressing the needs of children with serious emotional problems who are wards of the Department of Children and Family Services (DCFS). The revisions to the mental health clinic rules which were recommended by this advisory group were subsequently drafted and published as Part 130, Title 59 of the Illinois Administrative Code in late October.

A great deal of work went into redrafting the mental health clinic rule and it is quite clear that DMHDD and DCFS officials, in particular, view the new coverage as a critical tool for addressing deficiencies in the State's current array of outpatient services for low income children and adults with serious mental health problems. DCFS, for example, has long been the target of law suits, alleging that the agency fails to provide adequate mental health services to emotionally troubled juveniles assigned to its care. DMHDD officials also point to yawning gaps in the availability of local mental health services, especially for lower socioeconomic groups in society. Officials of both departments view the revised mental health clinic option as a means of generating the additional revenues necessary to make meaningful inroads into the backlog of unmet mental health needs in local communities across Illinois.

This report focuses exclusively on possible developmental disabilities financing options under Medicaid and, consequently, the comments offered are not necessarily directly applicable to the financing of mental health services, a policy area in which the present author claims no particular expertise. Nonetheless, it probably should be noted that the states' recent experiences in financing day habilitation services for persons with developmental disabilities through the "rehabilitative" or "clinic" services options offer sufficient grounds for proceeding with great caution.

In late 1988 and early 1989, HCFA notified a number of states that were covering freestanding daytime habilitation services under their Medicaid state plans ( e.g., Maine, Massachusetts and Arkansas) -- i.e., either as a "clinic" service or a "rehabilitative" service -- that FFP would be terminated because the types of services being furnished did not constitute "medical and remedial" services. Congress stepped in to protect these states by adding language to the 1989 reconciliation act which prohibits HCFA from withholding or terminating Medicaid funding for daytime habilitation services in states that had this coverage as

of June 30, 1989, pending the issuance of final federal regulations which clarify the elements of such services that are and are not subject to FFP. This new statutory provision, however, is silent with regard to the approval of pending or new state plan amendments dealing with the coverage of freestanding day habilitation services.

Work on revised rules governing the provision of medical rehabilitation and clinic services is just beginning within HCFA; as yet, there is no indication of when such regulations may be published as an NPRM. It may be months or it could take years. To date, the focus of HCFA regulatory initiative appears to be limited to day habilitation services for persons with developmental disabilities, although in the past, Agency officials have indicated that they have some of the same objections to coverage of outpatient mental health services as a Medicaid-reimbursable clinic or rehabilitative service. The best advice that can be offered at this point is to proceed carefully in implementing the expanded MH clinic option, making sure to fully document all Medicaid claims.

OBRA-89 (P.L. 101-508) includes a provision which codifies HCFA's existing regulatory definition of "rehabilitative services", without change. The inclusion of this new statutory definition was promoted by a number of national organizations that advocate on behalf of people with mental illnesses. They felt that elevating the regulatory definition to the statute would make it more difficult for HFCA to add further administrative constraints on the ways in which states use this financing option (e.g., by limiting Medicaid reimbursement to services furnished on the provider agency's premises). However, it should be noted that the definitional language itself restricts reimbursements to "medical and remedial services", which of course is precisely the basis upon which HCFA is attempting to deny states reimbursement for day habilitation services.

3. **Educationally Related Services**. Since final federal ICF/MR regulations were published in January, 1974, HCFA rules have prohibited the states from claiming Medicaid reimbursement for educational and vocational training services (42 CFR 441.13(b).

However, after the Office of the Inspector General (HHS) began to conduct a series of audits of state-operated ICF/MR facilities across the country in 1984 and press HCFA to disallow millions of dollars of Medicaid reimbursements to these facilities on the grounds that they were providing "educational services", HCFA decided (after receiving strong Congressional pressure) that there was a need for further clarification of the regulatory exclusion. Consequently, in September, 1985, the Agency added a new section (Section 4396) to the State Medicaid Manual to help states distinguish between non-allowable educational services and allowable habilitation services provided to residents of ICF/MRs and child psychiatric facilities. Section 4396 of the Manual

recognizes that reimbursement for a variety of the services required by youngsters with severe disabilities may be claimed both under Medicaid and under federal and state education statutes. Therefore, the Manual instructions adopt the position that Medicaid funds cannot be made available for services described in a child's Individualized Education Program (IEP) or otherwise required under federal and state education laws. These instructions also specify that FFP is not available under Medicaid to cover the cost of traditional education activities such as training in academic subjects.

By late last year, several converging developments led HCFA officials to conclude that revised regulatory policies were needed in this area. First, in 1985 a federal district court in Massachusetts rejected HCFA's position that Medicaid reimbursement could not be made available for services that are part of a child's IEP or which otherwise are required under federal/state education laws (Commonwealth of Massachusetts v. Heckler). Instead, the court concluded that the determination of whether a service is educational and, therefore, ineligible for FFP under the Medicaid program had to be based on the nature of the service rather than the methods the state uses to administer such services. This ruling later was upheld by the First Circuit Court of Appeals (Commonwealth of Massachusetts v. Bowen). In 1988, the U.S. Supreme Court also rejected HCFA's appeal in this case on jurisdictional grounds (Bowen v. Massachusetts), thus upholding the district court's original 1985 decision.

Second, the Education of the Handicapped Act Amendments of 1986 (P.L. 99-457) include a provision which specified that funds made available through P.L. 94-142 may not be used to satisfy a service commitment which otherwise would be paid for by other federal, state or local programs (including health programs, such as Medicaid), if these services were not being provided as part of a child's IEP. This language called into question HCFA's interpretations that: (a) Medicaid should be treated as "payor of last resort"; and (b) services covered under a child's IEP are not subject to Medicaid reimbursement.

Finally, Section 411(k)(3) of the Medicare Catastrophic Coverage Act of 1988 (P.L.100-360) specified that services which ordinarily would be eligible for Medicaid reimbursement under Title XIX, were they not part of a child's IEP, should be treated no differently when they are included in an eligible child's IEP. The Congressional report accompanying this legislation explicitly stated that, in adding this new statutory provision, the committee intended that FFP be made available through Medicaid to cover "related services" costs which HCFA previously had treated as non-reimbursable under its educational services exclusion.

In response to these legislative and judicial actions, HCFA published a Notice of Proposed Rulemaking (NPRM) on February 21,

1990 which proposes significant changes in the existing regulatory exclusion of educational and vocational training costs in an ICF/MR. While these rule changes, when and if they are published in final form, will apply only to the provision of educationally-related services in the context of the ICF/MR service coverage, they can be expected to serve as a strong precedent for other applications of Medicaid reimbursement to educationally related services, including services furnished to children through the local public schools, intermediate school districts and private educational agencies.

The February 21 NPRM specifies that FFP would not be made available through the Medicaid program for "formal educational or vocational services", including (in the area of educational services) training in traditional academic subjects such as science, history, literature, foreign languages and mathematics. With respect to educational services, HCFA explains that the subject matter rather than the setting, time of day, or class size is to be used as the basis of determining whether a service is educational in nature or an allowable Medicaid habilitation expenditure. Obviously, this interpretation is an attempt to draw the Agency's policies into line with federal court opinions in the Massachusetts case as well as the recent statutory revisions in Medicaid and Education of the Handicapped statutes.

The types of service interventions that potentially may be treated as Medicaid-reimbursable under the policies set forth in the February 21 NPRM obviously are quite broad. In practice, however, a state clearly will be on safer ground if it sticks to "health related" therapy services that traditionally have been recognized as reimbursable under Medicaid policy (e.g., physical therapy, occupational therapy, speech, hearing and audiology services, physiological services, nursing care, physician services, etc.). Moving too far beyond these boundaries is likely to draw criticism that the service being provided is not "medical or remedial" in nature and, therefore, cannot qualify for Medicaid reimbursement.

The Illinois State Board of Education (ISBE) and the State Department of Public Aid are in the process of negotiating an interagency agreement which will allow local educational agencies to claim Medicaid reimbursement for educationally-related services on behalf of children with disabilities, using local matching funds. This practice is already underway in several parts of the State. In fact, a number of proprietary firms have sprung up over the last few years that handle third party billings by local school boards in return for a commission or share of the additional third party revenues that are generated.

The proposed agreement between ISBE and DPA reportedly will be designed to permit local school agencies to bill Medicaid for such services as physical therapy, occupational therapy and speech and hearing services. It will deal separately with Medicaid

reimbursement for services to children ages 3 to 21, who are enrolled in preschool and school programs, and infants and toddlers ages 0 through 2, who are participating in early intervention services. Several pilot programs have been set up across the state to test procedures for third party billings through local school districts.

As of late October, a number of sticking points still needed to be resolved before a final agreement could be signed. One of these unresolved issues was how to handle DPA's general requirement that all services be "prior authorized" by a physician before they can be treated as a Medicaid-reimbursable expenses.

## VI. CONCLUSION

This report details a variety of ways in which the State of Illinois might use Medicaid funding more extensively to support the expansion and improvement of services to persons with developmental disabilities, statewide. The underlying message, however, throughout the report is that State officials must: (a) carefully evaluate whether any given application of Medicaid funding can be instituted in a manner that is consistent with the State's overarching goals for its citizens with developmental disabilities; and (b) be prepared to establish the necessary administrative infrastructure at the state and sub-state level to support the efficient and effective delivery of services to this population, whether or not they are financed in whole or in part through the federal-state Medicaid program. The report of the H.B. 69 Advisory Committee and the advent of a new Administration in Springfield offers an ideal opportunity to address these issues and set a new course for Illinois.

Exciting developments have occurred in Illinois's developmental disabilities service system over the past two years -- developments that hold out the promise of a better life for people with severe lifelong disabilities originating in children. But if these promises are to become a reality, numerous challenges need to be addressed over the next few years. Hopefully, this report makes at least a modest contribution to the ongoing effort to pinpoint basic problems that have to be resolved and identify possible solutions.

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